



STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
Margaret M. O'Neill Bldg., Third Floor, Suite 1
410 Federal Street
Dover, Delaware 19901
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The Honorable John Carney
Governor

John McNeal
SCPD Director

BRAIN INJURY COMMITTEE
April 2, 2018 – 2:00 PM
Smyrna Rest Area Conference Room, Smyrna, DE

PRESENT: Sharon **Lyons**, BIAD, Co-Chair; Sybil **Brown** (for Wendy Strauss),; Andrew **Buridan**, Brain Injury Advocate/Support Group; Vanessa **Deloach**, DHSS/DDDS, Assistant Director (for Rick Komalski); Donna **Dixon**, Bayhealth Neurosurgery; Katie **Freeman**, DSCYF, DPBHS, Psychologist (for Robert Dunleavy LCSW); Kristin **Harvey**, DDC (for Steve Yeatman); Michelle **Hood**, St. Francis LIFE; Dava **Newnam**, DHSS/DSAAPD; Nancy **Ranalli**, Easterseals, Director of Community Outreach; Dr. Ron **Sarg**, DCVA/MOAA; DLP; Zachary **Cooke**, Intern, SCPD and Dee **Rivard**, SCPD.

PARTICIPATED BY TELECONFERENCE (does not count toward quorum): Ann **Phillips**, Chair, Parent of a survivor; Linda **Brittingham**, Christiana Care Health System (CCHS); Debbie **Dunlap**, Advocate, Parent of a survivor; John **McNeal**, SCPD Director and survivor.

ABSENT: Carol **Barnett**, Planner II, DHSS/DSAAPD; GACEC; Thomas **Cairo**, Bayhealth Neurosurgery; Kathie **Cherry**, Governor's Advisory Council for Exceptional Citizens (GACEC); Tammy **Clifton**, DOL, DVR, VR Counselor I; Felicia **Connor**, Susan **Cowdery**, BCBS, Highmark Health Options; Jane **Crowley**, Dawn **Edwards**, DHSS, DSAAPD, Sr. Social Worker/Case Manager; Dr. Gerald **Gallucci**, Program Director, DHSS/DSAMH; Fran **Haggerty**, DOE; Jody **Hougentogler**, BIAD; Laura **Howard**, Deputy Director, DHSS/DSAAPD; Mary **Iampietro**; Nicol **Joseph**; Larence **Kirby**, DOS, Commission of Veterans Affairs, Executive Director; Cynthia **Mercer**, DHSS, DSAAPD, Planning Supervisor; Dale **Matusevich**, DOE, ECE, Education Associate, Transition Services (for Mary Ann Mieczkowski); Maria **Miller**; Carolyn **Morris**, DHSS/Office of Telehealth Planning & Development Medicine; Jennifer **Oppel**, Melissa A. **Smith**, DHSS, DSAAPD, Planner; Tiffany **Stewart**, DOE, Brandywine School District; Laura **Waterland**, Esquire, Community Legal Aide; Clarence **Watson**, DHSS, Medical Director; Leah **Woodall**, DHSS, MCH Deputy Director;

GUESTS

Marika Ginsburg-Block, University of Delaware; Mark N. Patrick, Caregiver

CALL TO ORDER

Co-Chair Sharon Lyons called the meeting to order at 2:01 p.m.

ADDITIONS/DELETIONS TO THE AGENDA

None

APPROVAL OF PREVIOUS MEETING'S MINUTES

Sharon asked if everyone was able to review the minutes of the last meeting calling for any additions, deletions, or changes. Kristin Harvey requested changes to the minutes to correct the spelling of her name throughout the document from "Kristen" to "Kristin" with two i's. Kristin also requested a change to correct DDS to the DD Act on the 3rd page. Katie Freeman requested a correction to Thomas Cairo's email from Thomas.Cairo@bayhealth.de to show his correct email address as: Thomas.Cario@bayhealth.org on page 7 of the minutes. Sharon called for discussion and not hearing any, Dr. Ron Sarg made a motion to approve the minutes as amended with Kristin Harvey seconding the motion that was unanimously approved by the members in attendance.

OLD BUSINESS

- Follow-up Items

TBI

- Sharon started off the discussion by asking about what language the committee wants and what the committee members think would work best to define brain injury. Kristin asked about the federal definition and whether or not it includes acquired brain injuries. The federal definition starts out saying an acquired injury to the brain caused by an external physical force resulting in total or partial functional disability but then it goes into more detail on to specifically state an open or closed brain injury. When Governor Carney signed the brain injury legislation Sharon looked up other state's definitions for their review and use; however, this state would not change the definition from a Traumatic Brain Injury (TBI).
- Marika Ginsburg-Block advised that we could be broader on the Special Education definition but not more limiting. States are free to name it what they want; however, it would have to match up.
- Andrew Burdan inquired if there is somewhere that the federal government has a list that is connected to that. Marika referred him to the first column of the handout stating that the federal definition of a Traumatic Brain Injury does not apply to brain injuries that are congenital or degenerative or to brain injuries induced by birth trauma.
- Katie Freeman is interested in including other anoxic brain injuries because it does mimic traumatic brain injuries although it is a minority of the other states. She would like to see Delaware's definition include other acquired brain injuries such as stroke and other anoxic brain injuries including stroke and tumors because the outcome so mirrors what a traumatic brain injury would look like.
- Marika stated that this was brought up at the last meeting and the Committee did not vote on this for a final decision. Kristin wondered if the DOE is staying away from acquired brain injuries in children because if a child has cerebral palsy and it impacts their activities of daily living then technically it would be considered a developmental disability.

Unfortunately, children with developmental disabilities only receive services until the age of 8 and then the child requires a different definition.

- Sharon inquired if everyone read the information that Dale sent referring to the huge 60 page document. What are your thoughts on what you are reading? Delaware only has 3 things under their definition. A discussion ensued noting that the Arkansas definition has a whole list of things as does New Mexico. When kids go back to schools, a lot of the schools don't understand the concussion issue. Sharon and Donna from Bayhealth and a couple of other people are trying to organize some kind of a conference to educate educators, trainers, and nurses in Delaware schools. A lot of people attended a few years ago when they provided training. Some school nurses actually believe that people only have concussive symptoms for 3 months and then they believe that the child is all better. People who work with individuals with concussions know that individuals can have concussive symptoms for 3, 4 or 5 years. We are lacking in educating people in the schools about concussions and brain injuries. Sharon tries to attend every meeting that she can in order to provide information on concussions. Other states list all of the behaviors and everything that they could be doing and we do not have that in Delaware.
- Marika advised that students could be served with a 504 plan under ADA rather than an IDEA plan. How do we know that this is a child that requires specially designed instruction? Sharon stated that concussion is completely different in that respect in that parents and educators try to get students back into the school setting as soon as possible.
- The Department of Education (DOE) would like to have specialized instruction to help them with technical experience and advice. Sharon is going to try to approach the Chief of Rehab Medicine at DuPont Hospital to see if she can speak to the head of the neurosurgical team to see if the hospital can do a special conference. It would take some planning and we would need to find a good location, we need that information. It is the same with adult and colleges as people don't understand how long the effects of a concussion lasts when 4 years out people are still experiencing difficulty speaking sentences with halting and gathering thoughts. Sharon can talk to someone and know that they still have a lot of the symptoms.
- Georgia kind of addresses the varying timeframes and that these injuries may intensify pre-existing problems over a period of time and Florida includes anoxia, which is a huge issue and is something that is missing from Delaware. While North Carolina's includes head injuries, cerebral vascular events, anoxia, tumors, and actually names out concussions in the definition and talks about not just brain injuries but the types of cognition issues, the language, the memory the judgement and abstract thinking issues. She believes that NC and Ohio's are two of the better definitions.
- John inquired if we are talking about the Department of Education definition of the schools and what it would require for reasonable accommodations stating that the schools are informed through their athletic programs about concussion protocol and repercussions to a concussion. Every one of the schools that has a sports program is required to abide by the concussion protocol standards. If other students are injured with a concussion, he would imagine that through an athletic program that the school should be aware of repercussions

of this and if they are not then there needs to be a higher level of education for them. Committee members agreed but did not know if that information filters down to everybody else and added that frequently there is never any follow through. John stated that voluntary education is one thing but there should be a level of required education for nurses and there is a route through the legislative process to address this issue. The challenging part is that not every school even has a school nurse so training requirements and education would have to be done at an administrative level. There needs to be at an administrative level or something regulated into the DOE to ensure that they have to have some type of protocol for concussions.

- Kristin inquired about the process for determining whether a child receives special education or falls under a 504 stating that she understood that it falls under an educational diagnostician to make the decision. Is there an overarching IEP Team because a child wouldn't have an IEP unless they were determined to need special education.
- Marika Ginsburg-Book who attended on behalf of Dale advised that right now the regulations state that an IEP Team will make the decision on whether or not a child needs special education or a 504. This is accomplished by an "Eligibility Meeting" with the IEP Team that would review all of the data that was collected by a school psychologist, most likely and then they would determine whether or not the student met the criteria.
- Debbie Dunlap shared information from her perspective, stating that Anne never went back to special education because she graduated. At that point in time, there was something about the two standard deviations in order to be able to qualify with IEPs and a lot of the peers that were younger than Anne, when they went back into the school system felt like they did not get the help from the teachers. She is unsure how things have changed; however, it causes a real problem when the person may look like they don't need help but they actually do need the help because they cannot remember, and do not have the executive functions or skills to be able to manage school work on their own.
- Minnesota recognizes a lot of these issues and Debbie Dunlap really loves the idea of having a conference to educate the nurses and teachers about what does qualify a student with a brain injury for the IEP in order to be able to get the extra help that they need. The IEP Teams make the determination.
- Part of the definition of a child with a disability in any category is "a child who has a disabling condition and requires specialized instruction" and you can show that the condition has an adverse effect on their education performance. At this time, we do not have a definition as to what an adverse effect on educational performance is in Delaware and the federal government does not provide that definition either. There are 9 states who have tried to define that for their states so right now in Delaware it is up to the IEP Team to decide whether or not the condition adversely affects the student's performance and therefore allow the student to receive specialized instruction. Some of the stakeholders in other categories are attempting to take this on and try to provide a definition that would apply to all categories and at this point it is pretty broad. Part of this committee's discussion at the last meeting stated that there could be a child who has a brain injury that did not have daily living impairment but has other sorts of impairment. Perhaps this

committee wants to recommend who should be required members of the IEP Team. Vanessa stated that it is like a chicken and egg thing since we do not have a definition for adverse effect.

- Marika agreed that at this point it is pretty broad. There could be a child with a brain injury who is not having functional need challenges but is having trouble in a different area. Some states are much narrower and must be measured by a test rather than by interview and observation. The group working on this in Delaware now is looking for a broader definition. Kristin felt that the federal definition actually does a good job.
- Katie appreciated the broader definition because when working with kids, sometimes it is harder to demonstrate through the testing with two standard deviations; however, if you can work with observations to make the case that the child meets the criteria. It tends to work better for the majority of kids to not have it be super specified how it has to be. Kristin concurred and also agreed with Katie that North Carolina's language is very robust. She likes that it also includes strokes and aneurysm, which are things that the committee as a whole had discussed. This could possibly help the Brain Injury Committee because it also talks about how a brain injury can occur with a single event or from a series of events. She also believes that the committee is uniquely situated to recommend who should be on the IEP Team.
- Katie added that someone cannot demand that a person from outside of the school be part of the team; however, they can say that the school nurse must be a part of the IEP Team.
- Marika stated that right now it does require medical documentation but doesn't require that the school nurse be part of the team. This committee may specify who should be on the team and what documentation should be required. That is pretty open. Within the eligibility criteria you may specify to that category who should be on the team and what documentation is required. This committee also has to weigh the costs and benefits; are they available and whether or not it is a good use of time.
- Marika recapped the committee's discussion stating that it sounds like this is the consensus of the group and inquired if this should be an official recommendation of the committee or if the committee wanted her to report back on what was discussed. Marika clarified that the committee is not making a recommendation to change the category name of traumatic brain injury definition; however, there was a recommendation to include acquired brain injury conditions as identified in the North Carolina regulations and to recommend that a school nurse be a required member of the IEP Team. Including the NC conditions as a condition for Delaware and ensuring that the school nurse is a required member of the IEP Team. Another recommendation of the committee is to remove from Delaware's that they have to show an adaptive functioning impairment.
- Marika advised that she will share these recommendations with the DOE and their legal team who will ensure that we are in compliance with the federal regulations. The goal is for this to come out in July for a public comment period. She will make a draft and send it to the entire team for review so that if there is anything she missed, the committee can let her know.

MOTION

- Vanessa DeLoach made a motion that the committee is recommending to:
 - Approve not changing the traumatic brain injury category name;
 - Recommend including acquired brain injury conditions in the 925 TBI Eligibility Regulations as identified in North Carolina's regulations;
 - Recommend that a school nurse become a required member of Delaware school IEP Teams; and
 - Remove the need to show an adaptive functioning impairment from Delaware's definition

as the Brain Injury Committee's official recommendation for amending 925 TBI Eligibility Regulations. This motion was seconded by Dava Newnam and unanimously approved by voting members in attendance.

DHIN

- Sharon announced that since no one from DHIN is in attendance for this meeting and Tom Cairo is not in attendance she is postponing this discussion for today's meeting.
- Katie Freeman advised that Tom Cairo asked that she put some things together for him and she did put some things together for committee members to look over for the next meeting on May 7.
- Sharon shared information that she was able to find a list of people who had brain injuries that at some point people were trying to keep track of brain injuries in Delaware and we were able to obtain numbers on two levels of brain injuries treated in Delaware and she will print out a copy of what she has to bring it to the May meeting. At least it was a start and someone was getting the information. Dee will also send an electronic copy of the information to the committee. Sharon advised that she is looking into offering certified brain training.

MEMBERSHIP UPDATE

- Karen McGloughlin was designated as Dr. Karyl Rattay's official designee. Unfortunately, she is not present today. John is checking to ensure that Karen McGloughlin was added to the distribution list and stated that she is dedicated to being a part of this Committee representing Public Health.
- Dava Newnam is present representing DSAAPD.
- Dr. Gerald Gallucci is the official representative from the Division of Substance Abuse & Mental Health (DSAMH). Although he is not present today, he did attend our last meeting.

BIC FUNDING OPPORTUNITIES

- Dava Newnam stated that Laura Howard looked into funding opportunities since the last meeting. Public Health is the agency that would be able to apply for these funding dollars. DSAPPD previously offered to partner with them last year; however, it required a 2 to 1 funding requirement and that is possibly why they did not move forward with it. Dava

suggested reaching out to DPH again to see if they are interested in moving forward during Delaware's current economic times with a 2 – 1 state match.

NEEDS ASSESSMENT SURVEY UPDATE

- Sharon asked members if they knew what information is recorded in the survey and what information is missing.
- Katie Freeman suggested updating the assessment survey information for the time-period covered from 2001 – 2006 to change it suggesting 2007 - 2017. There were a couple of places for dates and the committee may want to correct the ICD-9 to be changed to ICD-10. The committee may want to think about adding or asking what agencies and people have seen and what changes they observed since they last took this survey. It would also be advisable to inquire whether or not people have specialized training and if the answer is yes, the committee may want to specifically ask if they have certified brain training. It could be added to question 15 or 23.
- A discussion ensued about whether the committee wanted to do federal fiscal, state fiscal or calendar years. What is the purpose of the survey results and how is the information going to be used? To help applying for grants, probably federal grants. Dates would run 10/1 through 9/30 for federal fiscal year. Need to look at who we are asking to report and how they are structured. If we are looking at Medicaid then it would go by state fiscal year. DelDOT is state fiscal year. DSP would be state and Social Security would be by federal fiscal year. DDDS, DSAM, and DPH could pull everything on a state fiscal year.

RECOMMENDATION

- The committee agreed to ask for state fiscal year from 2007 to 2017 for the Needs Assessment Survey and to add two questions as follows: (1) What does the participating agency see as the biggest change or biggest growth area since they last completed the survey? (2) What does the participating agency/organization see as the greatest area of need in working with individuals with Traumatic Brain Injury (TBI) and where do they believe that we need to invest our resources? This allows participants to express their needs and the feds will want to see trends when the committee applies for funding. This is also to help us figure out what people across Delaware see as our greatest area of need and where we need to invest our resources. This way everyone is getting to express where they need the funds.
- John McNeal requested to take a step back to the Delaware Trauma Systems Registry and the data that Sharon pulled up which was through 2013, which was reported in 2014 and was approximately about the time that representation trickled off from DPH who gathered the information. DPH is where the information came from and John looked up to discover that there is pretty comprehensive data from DPH through 2016 available. The detail data is type 1 and 2 brain injury data. What he has been able to pull up since 2016 is so far not quite as detailed but that doesn't mean that the detailed data is not there. John will work with DPH to see what information that he can obtain from them before the next

meeting. The information that we are looking for may already be available and it is very detailed it goes by county, age, gender, race, mechanism of injury, ISS-R, patient status, NICU stay, and ICD-10 Codes. The difference between the types is that type 1 TBI covers patients with a moderate to prolonged loss of consciousness, injuries to the optic nerve pathways and type 2 TBI covers patients without a loss of consciousness. Dee will share John's findings with the committee. The information that Delaware Trauma System information is based on is the 8 acute treatment centers that participate.

- Sharon stated that the registry information does not include the military. Sharon also is not aware of whether or not the information included A. I. DuPont Hospital for Children. Ron Sarg does not know what the TBI number is because they do not treat it within the state.

NEW BUSINESS

- Sharon asked for any new business.
- There is a Stakeholder's feedback forum for the Administration for Community Living Plan. They are having a lot of in-services that are open for people to attend and find out what they are working on and what kind of gaps they have that support the TBI community. They have one for self-advocates, caregivers, and family, researchers, clinicians, providers, state agencies, and all stake holders. Get details from email. You can register 48-hours before the session. Stakeholders can listen to calls. There are not a lot of places and services for adults who have brain injuries. Sharon introduced Mark Patrick whose son has a brain injury and asked him if he would like to address the committee.
- Mark N. Patrick, father of a brain injury survivor spoke to the committee to let everyone know that Education, transportation, and logistic care is terrible. He advised that the Point of Hope does their best but he believes that they are overwhelmed. As a father of a survivor he is up at 5:30 a.m., until 10:00 p.m. working with the physical therapy aspects of his son's rehabilitation; however, he is not up to date on the educational rehabilitation for his son to be able to obtain the educational information that he needs to recover in order to learn to read and write again. It wears him out. His son's brain cells are firing and he just wants to keep challenging him and keep him going. He is retired and disabled himself and he could not find transportation the other day during an emergency for his son. If it wasn't for Point of Hope he doesn't know where he would be. It is sad but inspiring what they do there. If his son could somehow have a better hope of education for his son that would be a tremendous relief for him and a help to his son. He did not have much luck with the Robscott Center. It took him two years to get through the paperwork in order to get his son some help. Having to deal with pushing someone in spiritual, physical, and educational needs is exhausting. It has been quite a roller coaster ride. There has got to be something available for brain injury survivors out there. He called a vocational place trying to find help and they offered no hope, actually giving him a cold shoulder. They said his cognitive level is not high enough. Education, Education, Education is what he considers vitally important. His son has an anoxic brain injury and they want to know what his cognitive level is. How does he get his cognitive brain injury level increased? Cognitive rehabilitation is needed by his son and Bryn Mawr Rehabilitation just said to just take him home. It has definitely been a learning curve for his family. He also went to Star Research at the University of Delaware to try to obtain help for his

son. He is looking to obtain cognitive rehabilitation. His son finally has a neurologist that is grabbing the reins and now has his son down to 2 medicines from 16 that he was taking. Mr. Patrick stated that doesn't know where to go from here and implored the committee not to give up on individuals suffering from anoxic brain injury. Traumatic Brain Injury, what is it? He doesn't know what it is defined as. His son is in there. How do we help him get back out? His son knows that he made a mistake using the drugs but Mr. Patrick doesn't know what more help he can get.

- Kristin told Mr. Patrick that he has done an amazing job and that all brain injuries should be treated just like his son's has been treated with the unrelenting driving push from Mr. Patrick believing that his son could improve and get better.
- Mr. Patrick told committee members that his son knows that he made a mistake and that is what keeps driving him. However, Mr. Patrick doesn't know what else to do to help him especially since he and his wife are even taking care of his son's 6 year old child. What is all of this going to do to affect his grandchild? He thinks that his 6 year-old grandson has a problem. He keeps hitting a brick wall. Katie Freeman offered to speak with Mr. Patrick after the meeting ends. The committee as a whole told him not to give up even though it is exhausting. Mr. Patrick stated that his biggest obstacle right now is obtaining higher education rehabilitation and transportation for his son. Mr. Patrick thanked the committee for what they do. Mr. Patrick stated that he is not lazy but he does need a break.
- Andrew Burdan inquired if Mr. Patrick has applied to any of the personal respite care services. Mr. Patrick responded that he did apply to Easterseals and is also going to Sharon's Brain Injury Association of Delaware support group.
- John told Mr. Patrick that he sounds like the perfect person to participate as a part of this Brain Injury Committee and asked him to take it into consideration because this committee can definitely learn from those who are directly impacted. If time permits, there is certainly an open spot for him on this committee. Mr. Patrick advised that he will get with Sharon to see what he can come up with. He is grateful that this group cares.
- Sharon stated that in whole kids are well taken care of but it is not so good for the adults who struggle a lot with finding resources that are just not out there. Tammy Clifton is pretty involved with DVR and Sharon will check to see if they can find somebody in New Castle County who could see Mr. Patrick's son. John requested that Sharon double back with him to see what we can do to specifically address some of the direct needs that he is looking at right now. Mark can send John an email or call him on the phone. Dee will provide Mr. Patrick with John's information.

ANNOUNCEMENTS

- John McNeal shared an announcement about Dover opening a new Rehabilitation Hospital, for post-acute rehabilitation care. Sharon provided additional details sharing that Post-Acute Medical is a company that is offering short-term rehabilitation with emphasis on continuity of care and CAARP Certification. Ted is the CEO. Anthony Misatono also came to a BIC meeting a couple of years ago to present that they wanted to open a rehab center. Ted Warner is now the point of contact. What they plan to do is to provide continuity of care among and the continuum of care of recovery from a brain injury and once in their hospital patients are able to receive outpatient services at the Dover location. Patients can come back and work with the same therapists and

would have a longer timeframe to work on their brain injuries. John added that this Post-Acute Medical rehabilitation hospital will offer both inpatient and outpatient services and is exploring building another outpatient facility in Dover. The one question John had after his experience with HealthSouth is the definition of post-acute care. Post-Acute Medical stated that they would take Trach patients while or other acute care facilities like HealthSouth will not admit you. It will be interesting to find out what the new rehabilitation hospital's definition of post-acute care is. If you have any co-existing mental health condition HealthSouth or rehabilitation facility will not take you here in Delaware. What is the new rehabilitation hospital's conditions of acceptance? John stated that because HealthSouth is a private company that is privately run and they can make their own rules. The higher the level of need or care the higher the costs are. A lot of times when someone is discharged from Bryn Mawr and there is no place for them to go they end up sending them home and they are not ready to go home and then they end up going to one of the behavioral health center, and then send them to a mental health facility or to Governor Bacon, DHCI or out-of-state. There are a number of people who are just being sent out of state.

- Andrew Berman congratulated Sharon for the Brain Injury Association of Delaware's recent conference adding that he thought it was excellent, extremely informative and is telling everyone that he learned so much so quickly.

ADJOURNMENT

Motion to adjourn at 3:40 p.m., by Kristin Cosden, seconded by Vanessa DeLoach with the motion approved unanimously by voting members in attendance.

NEXT MEETING

The next Brain Injury Committee Meeting is scheduled for
Monday, May 7 at the
Smyrna Rest Area Conference Room
at 2:00 p.m.